

August 7, 2018

Steven D. Pearson, MD, MSc President Institute for Clinical and Economic Review Two Liberty Square, Ninth Floor Boston, MA 02109

Dear Dr. Pearson:

Cancer *Care*, joined by the Men's Health Network, is writing in response to requests for comments on ICER's Draft Evidence Report on treatments for high risk prostate cancer. We represent the voices of millions of cancer patients, survivors, and family members who are challenged each day by the financial burdens associated with cancer and its treatment. In the current environment of rising health care costs and cost shifting, we believe it is essential that the issue of value be focused on what is important to patients, rather than payer and provider priorities. To that end, please consider these concerns:

- 1. The ICER analysis is derived largely from clinical trial data, with minimal attempt to include real world evidence/data. Randomized Clinical Trials (RCTs) provide limited data, represent only a small segment of the population and do not represent how patients respond to these treatments in the real-world. They don't reflect patients' values and preferences, and are limited to the endpoints measured in the RCT's. In order for the impact to be fairly and accurately assessed, patient and clinical data registries should be examined.
- 2. While this ICER report includes almost one full page of insights from patients and patient groups, there is little transparency regarding how much of this feedback has been accepted and incorporated into the draft report. ICER should be transparent about the evidence on which its assessments are based.
- 3. Several variables important to patients, their families and caregivers are not considered in the comparative effectiveness analysis (e.g., potential to significantly reduce caregiver or broader family burden). The Value-Based Price Benchmarks section (#6) is blank and will be included in the revised evidence report released in late August. It remains to be seen if this will adequately incorporate patient priorities. Past experience suggests this might not be, and we hope you will incorporate quality of life outcomes that are truly patient-centric



- 4. ICER continues to include a budget impact threshold analysis. This arbitrarily establishes budget caps for societal expenditures on medical innovations and fundamentally ignores the value of innovation in healthcare and the value of care provided to individual patients.
- 5. A health sector and societal perspective are included in this report however the focus remains on drugs. For patients and society as a whole, costs extend much more broadly than this single element of healthcare. ICER analyses should consider the values associated with a broader continuum of care, since the use of drugs never occurs outside of this context.

We appreciate the opportunity to share these concerns with you, and hope that you will adjust your analyses to reflect what is important to patients. After all, each and every one of us stands in the shoes of a cancer patient or caregiver who deserves and is entitled to be treated as an individual, not a population.

Sincerely,

Ellen Miller Sonet

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